

## Work Group I. Education, Rights, Outreach, and Advocacy

### **Key Issue: PUBLIC ATTITUDES, AWARENESS, AND STIGMA**

**People fear that disclosure of their mental illness will have negative consequences for their employment, family, friendships, and participation in community life. Stigma discourages people from seeking treatment.**

Public misconceptions about mental illness produce stigma that results in fear, discrimination, and mistreatment. Stigma impedes timely diagnosis and appropriate treatment, which increases the risk of negative consequences for consumers, families, and others. There is no unified and authoritative voice raising awareness about mental illness and reaching out to populations at risk before crisis strikes.

The pervasive public stigma about mental illness negatively affects the allocation of federal, state, and local funding. Stigma also contributes to the disregard of consumer preferences for treatment and family involvement. Finally, limited insurance coverage for mental health perpetuates stigma by suggesting that mental illness is not a physical illness, despite medical evidence to the contrary.

### **Question: What data support the issue statements?**

**Answer:** The U.S. Surgeon General's 1999 report on mental health states "Stigma erodes confidence that mental disorders are valid, treatable health conditions. It leads people to avoid socializing, employing or working with, or renting to or living near persons who have a mental disorder, especially a severe disorder like schizophrenia. Stigma deters the public from wanting to pay for care and, thus, reduces consumers' access to resources and opportunities for treatment and social services" (Executive Summary, p. viii). Much research and numerous surveys support this statement, despite ample evidence that mental illness is based in physiology and is eminently treatable. The National Mental Health Association conducted national polls on schizophrenia and depression in 2003 and 2001, respectively. For schizophrenia, only 14 percent of the general public believed persons with schizophrenia could hold a job or raise a family. Only 27 percent of the general public believed schizophrenia was treatable. For depression, 35 percent of the general public was unfamiliar with the term "clinical depression" (a higher percentage than the year before), and 86 percent were unfamiliar with the term "generalized anxiety disorder" (a higher percentage than the year before). Only 55 percent of the general public accepted that depression was a disease; 31 percent categorized depression as "a state of mind you can snap out of." Forty-four percent of undiagnosed symptomatics believed they could handle their symptoms without any outside assistance.

### **Proposed Options**

- I.1. Form an independent organization consisting of representatives of state and local government, including the Michigan Surgeon General, consumers, advocacy organizations, and advertising and public relations industries to create a continuing campaign to educate the public that mental illness is physical illness.

- I.2. Support legislation that requires all insurers to offer coverage for the treatment of mental illnesses and addiction disorders that is equivalent to the coverage for all other disorders.
- I.3. Encourage the state's four public medical schools (U of M, WSU, MSU-CHM, MSU-COM) to work cooperatively on research projects:
- I.4. Enlist the support of the MEDC and local economic development groups to embellish the "life sciences corridor" by attracting to Michigan pharmaceutical and other related private industries that will capitalize on research into the causes and treatments of mental illness.
- I.5. Encourage mental health-related organizations located in Michigan to work cooperatively.
- I.6. Increase early identification/screening and prevention efforts to match those of other health conditions.

**Key Issue: ACCOUNTABILITY**

**The public mental health system is not sufficiently accountable to citizens that apply for, receive, or wish to appeal services, nor is it accountable to the state taxpayers.**

- There is no statewide consistent, objective mechanism for measuring contract and rights compliance of CMHSPs and their contract providers.
- Current methodologies for developing budgets and monitoring spending do not accurately assess the "true costs and benefits" of policy decisions because budgets and spending are tracked within individual "silos."
- Client surveys performed by CMHSPs are not uniform statewide and do not provide statistically significant data that may be used by DCH to improve the public mental health system.
- The Medicaid Fair Hearing process does not require clinical input when making decisions about amount, duration, and scope of services.
- Applicants and recipients of public mental health services who are not Medicaid eligible have no effective appeal mechanism.

**Question:** *How do we state the point about the lack of a requirement for clinical input for Medicaid Fair Hearings?*

**Answer:** According to current law, administrative law judges are *allowed* to use clinical expertise when conducting a Medicaid Fair Hearing, but they are not *required* to do so.

**Proposed Options**

- I.7. The state rights office will develop uniform methodologies and programs for monitoring the use of evidence-based practices; evaluating program outcomes, service quality, and the appropriateness of services delivered; auditing fund management; and client and applicant satisfaction.

- I.8. The state rights office will contract with an independent party (e.g., a public university, foundation, or nonprofit advocacy group) to assist with these programs, including the collection and analysis of client surveys and other data, and the preparation of an annual statewide report.
- I.9. Methodologies for monitoring funding needs and budgets will be designed to more accurately assess the “true” costs and benefits of public mental health services rather than measuring within individual program “silos.”
- I.10. The state rights office will administer Medicaid Fair Hearings and a corresponding hearing process for the non-Medicaid population, assuring clinical consultation for both.
- I.11. CMHSPs will maintain a standard database, created by the state rights office, on non-Medicaid applicants that were denied service. The information from it will be provided to the state rights office on a quarterly basis.
- I.12. All MDCH-CMHSP contracts, and all contracts within a CMHSP network, will be required to designate both Medicaid and non-Medicaid applicants and recipients as third-party contractual beneficiaries.

***Key Issue: INADEQUATE RIGHTS PROTECTION***

**People served by the public mental health system do not have adequate rights protection because the mechanisms in place are confusing, overwhelming, inconsistent, and lacking authority to take corrective action in response to legitimate complaints.**

Recipients of Michigan’s public mental health services have all the civil rights afforded the general population, plus several additional rights related specifically to those services. The statutory basis for the protection of the rights of those receiving services is the Michigan Mental Health Code and the federal Social Security Act. The current recipient rights system does not adequately protect the rights of consumers and their families.

- There is a strong perception of conflict of interest.
- Uniform interpretation of rights law, rules, and policy throughout the state is lacking.
- The rights information provided to consumers and their families is not “user friendly.”
- The state recipient rights office does not have the authority to correct serious and persistent issues of noncompliance without punishing the clients of the system.

***Question: Is the complexity and confusing nature of the rights protection program affected by the existence of two statutory bases?***

**Answer:** Yes. The work group’s overall recommendations are designed to reduce the complexity inherent in complying with both the federal Social Security Act (for service recipients who are eligible for Medicaid) and the Michigan Mental Health Code (for service recipients who are not eligible for Medicaid).

### *Proposed Options*

- I.13. The state recipient rights office is made a Type I/ autonomous agency within the MDCH or another part of the executive branch.
- I.14. Regarding systemic noncompliance issues, the state rights office and a CMHSP would initially pursue remediation through collaborative dialogue in which the CMHSP is involved in seeking solutions, after which the state rights office would determine the success of such steps. Once the dialogue is concluded, remedies recommended by the state rights office would be binding.
- I.15. The administration of any CMHSP whose network, after a series of graduated steps toward remedy, exceeds the prescribed ceiling of noncompliance with rights protocols, requirements, and performance on a systemic level, will be placed under receivership by the state.<sup>1</sup> Contracts between CMHSPs, middle managers, and end providers must address rights protection and compliance, including financial sanctions for inadequate rights performance.
- I.16. The state rights office becomes a “one-stop-shopping” center for *all* mental health and substance abuse rights matters, regardless of Medicaid eligibility.
- I.17. Local recipient rights offices (currently part of CMHSPs) are turned into local or regional offices that are staffed by and totally responsible to the state rights office.
- I.18. Legal counsel from the state rights office will be available to all local/regional offices.
- I.19. Local/regional recipient rights offices would provide regular education and training to all providers and service managers.
- I.20. The state rights office would engage in education, training, evaluation, and assistance to primary and secondary mental health consumers in navigating this and other human service systems.
- I.21. The rights office, perhaps in conjunction with an independent organization, will review current forms, handouts, brochures, booklets, and other materials that are used within the system to inform consumers and families about their rights and available programs and evaluate them for readability, utility, suitability, and cultural sensitivity. As necessary, the rights office will develop new materials in appropriate formats.
- I.22. The state rights office will examine recipient and applicant fatalities and sentinel events for issues of possible rights violations. On behalf of a deceased recipient or applicant, an executor, administrator, or other person having authority to act should be given legal standing to initiate a grievance of a denial of service. If permitted by federal law, such standing should also be available to the deceased individual’s family members (as presently defined in the Mental Health Code) or agents designated through an advance psychiatric directive.

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<sup>1</sup> The evaluation criteria for CMH compliance would not necessarily be those in place today.

- I.23. Adopt legislation to sanction the preeminence of consumers and their families in the development and maintenance of their treatment experience. Such legislation could include (1) promoting and governing use of advance psychiatric directives (APD) for adults, overseen by the state rights office; (2) allowing medical guardians to approve of inpatient psychiatric care; or (3) requiring that family-centered planning be used with adult recipients who desire and request the involvement of willing family members.
- I.24. Require service providers to formally offer and strongly encourage the establishment of advance psychiatric directives for those who don't have one in place.